RARE VOICE Awards

THE 12TH ANNUAL

RARE VOICE AWARDS

DECEMBER 13, 2023
ARENA STAGE, WASHINGTON, D.C.

In honor of advocates who champion and amplify the rare disease patient voice in state and federal policy.

PRESENTED BY

sanofi

EVERYLIFE FOUNDATION FOR RARE DISEASES

RDLA Rare Disease Legislative Advocates

Thank you to our 2023 RareVoice Award Sponsors

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RARE VOICE Awards

EVENT PROGRAM

Masters of Ceremonies

Cristina Casanova Might

Victoria Might

Announcement of the RareVoice Award Recipients

Congressional Leadership Award

Federal Advocacy: Congressional Staff

Federal Advocacy: Patient Advocate or Organization

Federal Advocacy: Federal Agency Staff

State Advocacy: State Legislator

State Advocacy: Patient Advocate or Organization

Federal or State Advocacy: Youth and Teen

Diversity Empowerment: Patient Advocate or Organization

Artist-To-Advocate

@RareAdvocates

#RareVoice2023 // RareAdvocates.org

MASTERS OF CEREMONIES

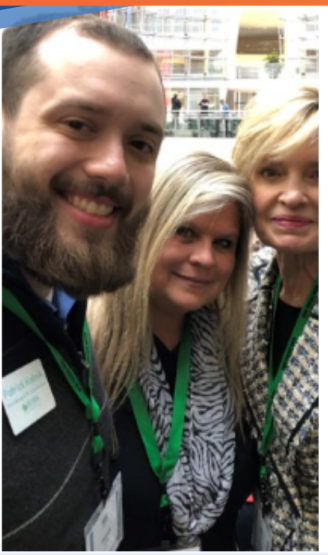
CRISTINA CASANOVA MIGHT

VICTORIA MIGHT

Our masters of ceremonies are a dynamic mother-daughter duo, Cristina Casanova Might and Victoria Might. Cristina, a beacon of advocacy and innovation, is the CEO at Welcomed Co and a board member at EveryLife Foundation for Rare Diseases. Her journey, marked by love, loss, and unwavering dedication, has been a tapestry woven with threads of advocacy, leadership, research, education, and policy. Cristina's life has been profoundly touched by rare diseases, first by her son Buddy's journey followed by her own diagnosis. These experiences have forged in her a unique perspective and an arsenal of skills aimed at ending the diagnostic and therapeutic odyssey for patients and their families.

Her daughter, Victoria Might, is a vibrant 12-year-old with a passion for competitive dancing. Victoria's spirit and creativity have been instrumental in the journey of Welcomed Co., embodying a youthful perspective that champions inclusivity and accessibility. Together, they have cultivated a space where beauty and functionality converge to meet the unique needs of individuals, ensuring that everyone feels welcomed and cherished.

CHANGING POLICY, SAVING LIVES



EVERYLIFE FOUNDATION FOR RARE DISEASES

The EveryLife Foundation for Rare Diseases is a nonprofit, nonpartisan organization dedicated to empowering the rare disease patient community to advocate for impactful, science-driven legislation and policy that advances the equitable development of and access to lifesaving diagnoses, treatments and cures.

@EveryLifeOrg

Everylifefoundation.org

RDLA
Rare Disease Legislative Advocates
POWERED BY THE EVERYLIFE FOUNDATION

Rare Disease Legislative Advocates is a program of the EveryLife Foundation for Rare Diseases designed to support the advocacy of all rare disease patients and organizations.

@RareAdvocates

rareadvocates.org

RARE VOICE Awards

Official RareVoice Correspondent

Stephanie Riordan

@rare_advocates

Follow the Rare Disease Legislative Advocates (RDLA) on Instagram @Rare_Advocates for behind the scenes content from our RareVoice correspondent.

Takeda

RAREHUB

WASHINGTON D.C.

OFFICE SPACE NOW AVAILABLE

The Rare Hub provides patient-focused organizations with the benefits of downtown Washington, D.C. office space at affordable rental costs. The Rare Hub is a space to foster collaboration, advocacy and innovation among rare disease organizations. Additionally, Rare Hub partners may use the Rare Hub as their physical D.C. address, providing significant financial savings.

A one-person furnished office space is $1,050 per month per 12-month lease. Benefits include mail services, conference room usage, networking opportunities, logo recognition, and more.

Visit RareHubDC.org or email sriordan@everylifefoundation.org to inquire

Current Partners

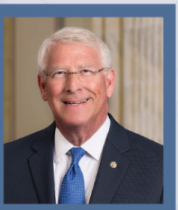
EveryLife Foundation for Rare Diseases · FSR Foundation for Sarcoidosis Research · Global Genes Allies in Rare Disease · Little Hercules Foundation · National Fragile X Foundation · National MPS Society Support for Families. Research for a Cure. · Parent Project Muscular Dystrophy Join the Fight. End Duchenne. · RAAP Rare Access Action Project · Sick Cells · Syngap Foundation Research Education Advocacy · UDNF Undiagnosed Diseases Network Foundation · VHL Alliance

RARE DISEASE CONGRESSIONAL CAUCUS

Thank you to our Rare Disease Congressional Caucus Co-Chairs and Members

Representative
Doris Matsui (CA)

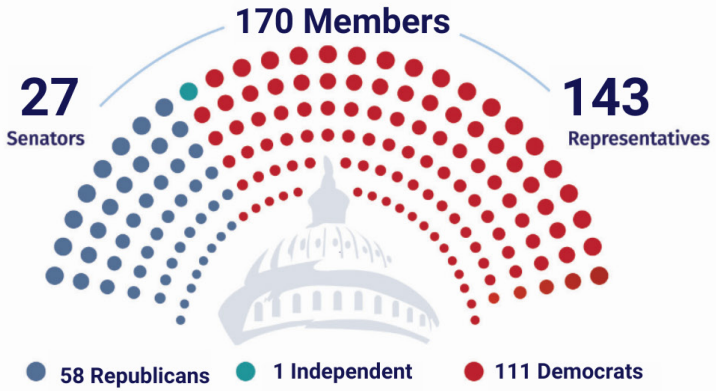
Representative
Gus Bilirakis (FL)



Senator
Roger Wicker (MS)

Senator
Amy Klobuchar (MN)

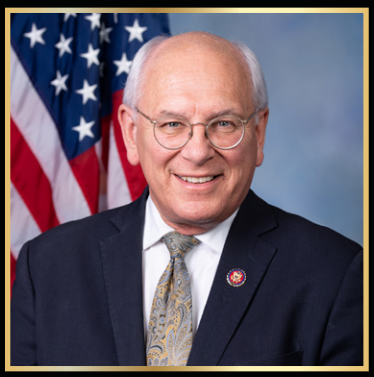
The Rare Disease Congressional Caucus is a bipartisan, bicameral caucus to voice constituent concerns, collaborate on ideas, facilitate conversations between the medical and patient community and build support for legislation that will improve the lives of people with rare diseases.



Ask your Member to join today.

RARECAUCUS.ORG

CONGRESSIONAL LEADERSHIP AWARD



REPRESENTATIVE PAUL TONKO (NY)

Congressman Paul Tonko represents New York's 20th Congressional District, including the communities of Albany, Schenectady, Troy, and Saratoga Springs.

He is serving his eighth term after first being sworn into Congress in 2009.

Congressman Tonko serves on the Energy and Commerce Committee, the oldest standing committee in the House, created in December of 1795, and serves as the Ranking Member of the Energy and Commerce Subcommittee on Environment, Manufacturing, & Critical Materials. In addition, Congressman Tonko serves on the Energy and Commerce Subcommittee on Energy, Climate, and Grid Security, the Subcommittee on Oversight & Investigations, and is a member of the Committee on Science, Space, and Technology.

REPRESENTATIVE BRETT GUTHRIE (KY)

Congressman Brett Guthrie represents the 2nd Congressional District of Kentucky. Following his military service in the Army, Guthrie joined a Bowling Green, Ky., based manufacturing business that was started by his father and represented the 32nd District in the Kentucky Senate. Guthrie was elected to the U.S. House of Representatives in 2008 and currently serves as the Chair of the Health Subcommittee on the House Energy and Commerce Committee and as a Deputy Whip within the House Republican Conference.

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FEDERAL ADVOCACY CONGRESSIONAL STAFF

AMANDA LINCOLN

Senate Committee on Health, Education, Labor, and Pensions - Modernizing the Accelerated Approval Pathway Act, S. 4446, MOBILE Health Care Act, S. 958; Telehealth Modernization Act, S. 368

Amanda Lincoln serves as Republican Staff Director to the Senate Health, Education, Labor, and Pensions (HELP) Committee for Ranking Member Bill Cassidy (R-LA). She has previously worked as Legislative Director for Senator Mike Enzi (R-WY), and as Health Policy Director for Senate HELP Committee members Senators Bill Cassidy, Susan Collins (R-ME), and Mike Enzi. During her tenure on Capitol Hill she has developed and shepherded numerous policies throughout the legislative process, including serving as Cassidy's top staffer on the Infrastructure Investment and Jobs Act, and leading major efforts on drug pricing, FDA reform, NIH modernization, and mental health.

LUCAS LAM

Office of Representative Eric Swalwell (CA-14)- Precision Medicine Answers for Kids Today Act

Lucas Lam is a Health Legislative Assistant with Congressman Eric Swalwell. Prior to working on the hill, Lucas worked in government relations for a large pharmaceutical company and the home health industry, focusing on strategic partnerships with patient advocacy groups and government stakeholders, and COVID-19 preparedness and response, strategic partnerships with patient advocacy groups and government stakeholders, and COVID-19 preparedness and response. In his current capacity, Lucas has worked on legislation, regulatory comments, letters to agency heads, and stakeholder engagement related to Medicare and Medicaid coverage/ payments, the FDA approval process, locality pay issues, and TSA handling of medically necessary products. He also leads Congressman Swalwell's engagement as the founder and Co-Chair of the Congressional Personalized Medicine Caucus, a forum that engages Members and biotech companies in a constructive dialogue about legislative and regulatory policies in the fields of personalized medicine, cell and gene therapies, and genetic testing.

KELSI WILSON

Office of Representative Brad Wenstrup (OH-2), formerly Office of Representative Kevin Brady (TX-8) - Medicare coverage of IVIG for primary immunodeficiency disease

Kelsi joined Congressman Wenstrup's office in 2022. In her current role, Kelsi advises on health, labor, social security, workforce, and welfare matters. Congressman Wenstrup currently serves on the House Committee on Ways and Means, the House Permanent Select Committee on Intelligence, Chairman of the Select Subcommittee on the Coronavirus Pandemic, and as a Co-Chair of the GOP Doctors Caucus. Previously, Kelsi served as a Legislative Assistant to former Chairman of the House Ways and Means Committee, Kevin Brady. Prior to her time in Congressman Brady's office, Kelsi served as a Policy Assistant at both Hance Scarborough, LLP and Meyers and Associates, LLC. Kelsi is proud Texas Tech University alum.

IJEOMA EGEKEZE

Office of Senator Patty Murray (WA), formerly Office of Senator Chris Van Hollen (MD) - Sickle Cell Care Expansion Act

Ijeoma Egekeze is from Piscataway Township, New Jersey. Egekeze earned her bachelors from Georgetown University in 2013 and studied at George Washington University School of Public Health and Health Services from 2013 - 2015 to earn her MPH, Health Policy. Egekeze has worked with the CDC, US Department of Health Human Services, and Center for Health and Center Equity, Office of the Surgeon General, and the Foundation for AIDS Research. Egekeze has also served as a legislative correspondent for Senator Booker, a health policy fellow for Representative Stacey Plaskett, and a legislative assistant for Representative David Scott. Through her career, Egekeze has been passionate about equal access to healthcare and ensures that the voice is heard through ever meeting and interaction with the rare disease community.

PATIENT ADVOCATE OR ORGANIZATION

MINDY HENDERSON AND MADISON LAWSON

Muscular Dystrophy Association – Accessibility Provisions in Federal Aviation Administration (FAA) Reauthorization bill

Driven to build a world that welcomes and includes EVERYONE, Mindy Henderson is a powerful leader in disability rights, with specific interests in employment, accessible air travel, universal design, and inclusive style. Mindy's book, "The Truth About Things That Suck" is for anyone who wants a new perspective on adversity when times get tough. The book teaches us ALL that the wrong mindset can be far more disabling than what any wheelchair might represent. As the Editor-In-Chief of the Muscular Dystrophy Association's Quest Media adaptive lifestyle platform, Mindy's mission is to empower the neuromuscular disease community - and the broader community of individuals with disabilities - to live their lives to their fullest potential.

Madison Lawson is a journalist, model, and disability rights activist whose work has been featured in publications including Vogue, Glamour, Teen Vogue, Allure, Hunger, and more. Lawson draws inspiration from the mother of the disability rights movement and her late friend Judy Heumann who made the world a better place for every person who has a disability. Although Lawson recognizes nobody could ever fill the hole that losing Heumann left in the world, her legacy inspires her to wake up every day recognizing that there is a lot more work to be done and to continue pushing that needle of inclusion forward.

SHELLY HOOVER

ACT for ALS Act and Elizabeth Dole Home Care Act

Living with ALS since 2013, Shelly is an advocate for veterans and others living with ALS. The disease has taken her ability to speak but not her voice. She works relentlessly to advance legislation and improve policies. Shelly is a former public-school administrator and current grandmother of five. She lives with her husband, Steve, in North Carolina. She is active with many ALS organizations and efforts including I AM ALS, Veterans Affairs Team; I AM ALS, Legislative Affairs Team; VA, ALS Executive Committee; General Mik Project Lead; CDMRP ALS Research Program, Consumer Reviewer; Healey Platform Trial, Recruitment & Retention Team; NEALS, Research Ambassador; NEALS, PeACE Committee Member; Answer ALS, Research Ambassador; FDA Industry Guidance Document, ALSA Patient Advisory Committee; FDA Guidance Meeting, 2015; and Former Board Member of the Greater Sacramento ALS Association.

LYMPHEDEMA ADVOCACY GROUP

Lymphedema Treatment Act

The Lymphedema Advocacy Group is an all-volunteer organization of patients, caregivers, healthcare professionals, and industry partners, founded in 2010 by Heather Ferguson after one of her sons was born with congenital lymphedema. Our mission is to advance lymphedema care in the United States through improved insurance coverage for the diagnosis and treatment of the disease. For this purpose, we work to increase awareness of and education about lymphedema amongst lawmakers, insurance providers, and other relevant entities. The Lymphedema Advocacy Group has led successful efforts to improve coverage through both state and federal legislation, as well as through regulatory action and policy decisions. We encourage all members of the lymphedema community to become active participants in this process and empower patients by providing them with the knowledge, tools, and guidance needed to effectively advocate for themselves and others.

BRANDILEE SAWYER

Finn Sawyer Act

BrandiLee is Director of Patient Advocacy & Engagement at SHEPHERD. She worked in the nonprofit world prior to becoming a mom, but her life-calling became clear after her youngest son Finn battled and died from a rare and aggressive cancer called rhabdomyosarcoma. She will always grieve the loss of Finn, but uses her grief and anger in a productive way. After being thrust into the cancer world overnight and in the worst way, she became devoted to changing the oncology space to make cancer survivable for all cancer patients.

BrandiLee is a self-taught "momcologist". In addition to helping advance treatment options for rhabdomyosarcoma, she is passionate about connecting patients to treatment options and educating them about the importance of sequencing tumor tissue. BrandiLee also advocates for recently introduced federal cancer legislation named in honor of Finn, the Finn Sawyer Access to Cancer Testing Act, which would extend coverage of molecular diagnostics at the time of diagnosis for all cancer patients.

The Cost of Delayed Diagnosis in Rare Disease: *A Health Economic Study*

The Impact of Delayed Diagnosis in Rare Disease

Navigating a rare disease diagnosis can require more than 6 years and 17 medical interventions, on average, after symptoms begin, including emergency room visits and out-of-state specialist appointments.1

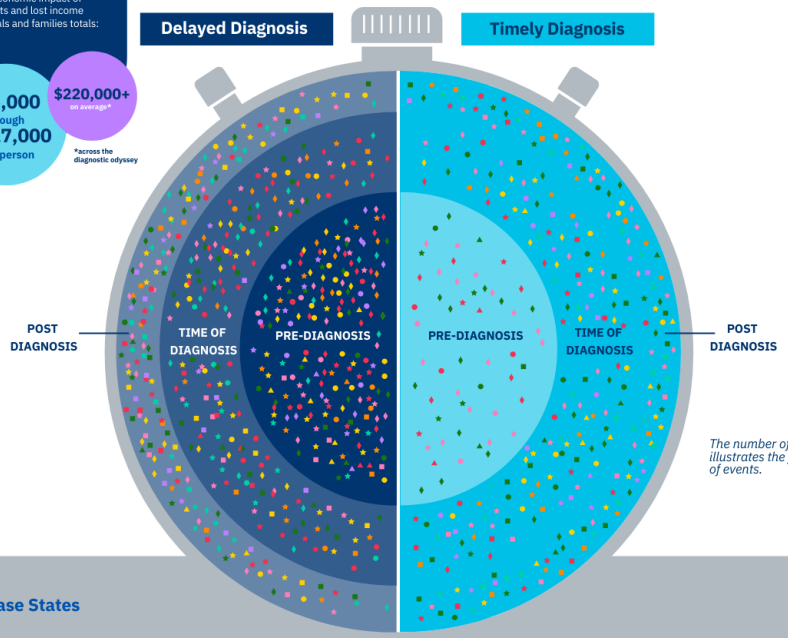
Our in-depth look at the diagnostic odyssey across seven rare diseases found the economic impact of medical costs and lost income for individuals and families totals:

$86,000 through $517,000 per person

$220,000+ on average*

*across the diagnostic odyssey

Every Minute Matters



The number of shapes illustrates the frequency of events.

Disease States

- Duchenne (DMD)
- Pompe
- Adrenoleukodystrophy
- (ALD) Severe Combined Immunodeficiency (SCID)
- Fragile X Syndrome (FXS)
- Wilson Disease (WD)
- Generalized Myasthenia Gravis (gMG)

Journey Map Categories

- **Typical Accompanying Diagnosis:** Anemia, liver failure (Wilson), cognitive impairment, seizures (ALD), Gait issues (Duchenne)
- **Testing & Procedures:** Cognitive deficit testing (Fragile X), muscle biopsy (gMG)
- **Events:** Cardiac Failure (Pompe), Hospitalization, Death (multiple diseases)
- **Specialists:** Palliative care, total care team (ALD), orthopedist (gMG)
- **Treatments & Supporting Therapies:** Auditory therapy, feeding tube (SCID)

Examples are not exhaustive

ACTION IS KEY TO SECURING TIMELY DIAGNOSIS

The EveryLife Foundation is working to develop policies at the state and federal levels to reduce time to diagnosis. For more information on how you can get involved and support this effort, please visit **everylifefoundation.org** or contact us at **info@everylifefoundation.org.**

FEDERAL ADVOCACY: FEDERAL AGENCY STAFF

PHILIP (PJ) BROOKS, PH.D.

National Center of Advancing Translations Sciences (NCATS)

Philip J. (P.J.) Brooks is the Deputy Director of NCATS' Division of Rare Diseases Research Innovation. He also is the working group co-coordinator for the NIH Common Fund program on Somatic Cell Genome Editing, one of the leaders of the Platform Vector Gene Therapy (PaVe-GT) pilot project and the co-chair of the Bespoke Gene Therapy Consortium(link is external). He also represents NCATS in the International Rare Diseases Research Consortium (IRDiRC).

In May 2022, Brooks was selected as the recipient of the 2022 Sonia Skarlatos Public Service Award(link is external) by the American Society of Gene & Cell Therapy for consistently fostering and enhancing the field of gene and cell therapy.

Brooks received his doctorate in neurobiology from The University of North Carolina at Chapel Hill. After completing a postdoctoral fellowship at The Rockefeller University, he became an investigator in the NIH intramural program, where he developed an internationally recognized research program, including research on rare neurologic diseases resulting from defective DNA repair, including xeroderma pigmentosum, Cockayne syndrome and Fanconi anemia.

KELLY BUCKLAND

U.S. Department of Transportation (DOT)

Kelly Buckland is a person with a disability who has been actively involved in disability issues since 1979. He served for over twenty years as the Executive Director of the Living Independence Network Corp. and the Idaho State Independent Living Council in Boise, Idaho. Kelly graduated from Boise State University with a B.A. in Social Work and Drake University with a Masters in Rehabilitation Counseling.

Kelly has been honored with numerous state and national awards, including the University of Idaho President's Medallion, the Hewlett-Packard Distinguished Achievement in Human Rights Award, Outstanding Alumni, Boise State University and Outstanding Alumni, Drake University.

Kelly has testified before Congress numerous times on issues such as universal health care, Fair Housing, appropriations for centers for independent living, Olmstead and COVID 19.

Additionally, Kelly has a long history with the National Council on Independent Living (NCIL). He has served on numerous NCIL Legislative and Advocacy Subcommittees and other standing NCIL committees, the NCIL Governing Board since 1998, as NCIL Vice-President from 2001-2005, and as NCIL President from 2005 to 2009 and Executive Director from 2009 to July of 2021.

Kelly currently serves as the Disability Policy Advisor, at the US Department of Transportation in the Secretary's office. He has served in this position since September 2021.

2022 RAREVOICE AWARDEES

Aisling McDonough

Jay Eberle

Joni Rutter

Amy Oliver

Assembly Member Brian Maienschein

Shannah Hudson

Owen Maxfield and Claire Oliver

Leah Campbell

Ali SP

STATE ADVOCACY: STATE LEGISLATOR

REPRESENTATIVE LIZ REYER OF MINNESOTA

First elected in 2020, Liz Reyer serves as State Representative for Eagan, Minnesota. She currently serves as Vice Chair of the Capital Investment Committee and also sits on the Health Finance and Policy, Human Services Finance, and Workforce Development Finance and Policy Committees.

Outside of the legislature, Liz has more than 30 years of business and leadership experience, including 12 years at Blue Cross in Eagan. Professionally, she focuses on understanding needs and implementing cost-effective and people-centered solutions. She also wrote a business advice column in the Star Tribune for about 10 years, ending in 2020.

She has a bachelor's degree in Chinese from the University of Minnesota, a master's degree in Political Science from Ohio State University, and a certificate in Executive Coaching from Royal Roads University.

Liz and her husband Jim have been married for 30 years and have four adult kids, a cat, and a rescue dog. In her free time, she enjoys hiking and kayaking, yoga, parks, cooking, and studying foreign languages.

REPRESENTATIVE BRIAN HILL OF OKLAHOMA

Representative Brian Hill serves the Oklahoma House of Representatives; his 47th District encompasses Mustang, Oklahoma City, and Tuttle, Oklahoma. Hill dedicates his time at the capital, to serving in order to lead. He holds the title of Assistant Floor Leader and as Vice Chair of Rules, among a seat on the Appropriations and Budget Committee.

Hill is married to Melissa, whom he met at Southwestern Christian University. Together they have been blessed with two children, Eleanor and Josiah. The family resides on a farm in Mustang, Oklahoma.

Hill and his family serve their community in volunteering for local non-profit organizations. In doing so, he was able to meet a young woman, who used her voice to help him plant a seed to shape legislation in Oklahoma. He was honored to be able to serve the Great State of Oklahoma in paving what will most undoubtedly be a long road to accessibility, and providing a higher quality of life to those who live in Oklahoma who are most impacted by the need for accessibility.

REPRESENTATIVE CARRIE RHEINGANS OF MICHIGAN

State Rep. Carrie Rheingans is serving her first term representing Michigan's 47th House District, which includes parts of Jackson County and Washtenaw County.

Rep. Rheingans believes that every policy issue is a health issue. Community and individual health depend on the building blocks of our daily lives — community safety, economic well-being, meaningful relationships, affordable food, the built and natural environment, high-speed internet access and a functioning government with functioning services. Her passion and career have been in the service of advancing health equity, focused on uplifting minority groups, such as Black, Indigenous, people of color, rural communities, immigrants and LGBTQ+ folks throughout Michigan.

Rep. Rheingans is active in the community. She serves on the Washtenaw County Board of Health, Washtenaw Emergency Medical Services Commission, and is vice chair of programming for the Ann Arbor Democratic Club and is a member of the American Federation of Teachers Local 624.

REPRESENTATIVE NATALIE MIHALEK OF PENNSYLVANIA

Natalie Mihalek was elected to the Pennsylvania House of Representatives in 2018 to represent the 40th Legislative District.

Native to the Pittsburgh area, Mihalek's commitment to public service began as member of the Girl Scouts of America (GSA), where she received the GSA Gold Award, scouting's highest achievement. After high school, she enlisted in the U.S. Navy, and served in the elite nuclear power program, of which only 1% of the sailors admitted are women.

After her military service, she attended the University of Pittsburgh, earned bachelor's and law degrees to then work in the Allegheny County District Attorney's Office. There, she worked closely with victims and police to prosecute cases. In addition to her work in criminal justice, Mihalek also owned a successful small business and has worked in finance.

As a legislator and working mother, Mihalek is a commonsense legislator who stands for fiscal conservatism, right-sizing government, assisting veterans, strong education and safe communities. She is known for bringing the concerns of her constituents directly to Harrisburg.

She currently serves on the Consumer Protection, Technology and Utilities and the Insurance Committees. She is also a member of the House Appropriations Committee.

STATE ADVOCACY: PATIENT ADVOCATE OR ORGANIZATION

TEXAS RARE ALLIANCE

Newborn Screening RUSP Alignment Legislation in Texas

Texas Rare Alliance is a Texas-based 501(c)3 nonprofit rare disease advocacy organization, dedicated to improving access and health outcomes for the nearly 3 million Texans living with a rare disease. through education, advocacy, and policy reform initiatives. A specific rare disease may affect only a small group of people or even just 1 person. When counted together as a whole community, there are approximately 3 million Texans living with a rare disease. They are committed to breaking down existing health access barriers via education, advocacy, and policy reforms. They accomplish their goals by working collaboratively with a diverse group of rare disease community stakeholders to improve the lives and health outcomes of the greater rare disease community.

ANNELIESE AND AMELIA WILLIAMS

Indiana Rare Disease Advisory Counsel legislation, HB 1201

Anneliese and Amelia Williams are twin rare disease patient advocates from West Lafayette, Indiana. They are both seniors in Public Health at Purdue University. Amelia, diagnosed with Ehlers-Danlos Syndrome, Gastroparesis, and Narcolepsy, began her advocacy work in 2021 through the Young Adult Rare Representative (YARR) Program which Anneliese then joined following her 2022 diagnosis with Guillain-Barre Syndrome. They both participated in the 2022 YARR Leadership Academy where they learned about the importance of Rare Disease Advisory Councils for representing the rare disease community in state-level policy but discovered that Indiana did not have one. Under the mentorship of advocates from other states, they formed the Indiana Rare Coalition, a group of over 15 rare disease stakeholders in Indiana. With the support of this coalition, lobbyist Lou Belch, and representative Cindy Ledbetter, Anneliese and Amelia led the effort to establish an Indiana rare disease advisory council through the passage of HB1201.

WANDA SMITH

AP7: The California Cognitive Health Genomics Initiative

After watching her mother Sara lose her ability to communicate, Wanda knew she had to become the voice for Sara and others in need of treatment and healthcare change for dementia. Sara had a rare genetic form of frontotemporal dementia. Over 40 years Wanda has become that voice. She organized the first advocacy for Alzheimer's in California which passed innovative legislation. She serves as an assembly member of the California Senior Legislature (CSL) representing district PSA22 and is a leader on the San Diego County Aging and Independence Council.

She has positioned FTD in areas where it would otherwise not have visibility and helps to ensure its awareness as a rare dementia. Advocating for genetic testing to improve dementia diagnosis is a priority for Wanda. She eagerly works toward the day when a treatment or cure is available for this terrible array of neurodegenerative genetic diseases.

ANNETTE LOGAN-PARKER

Nevada SB 221

Annette Logan-Parker, a former nurse, is the Founder and CEO of Cure 4 The Kids Foundation (C4K), a tax-exempt institution in Nevada committed to addressing childhood cancer and rare diseases. In addition to her leadership at C4K, she shoulders the vital responsibility of Chair at the Nevada Rare Disease Advisory Council (NVRDAC). Annette's active participation in NVRDAC revolves around advocating for systemic policy changes that aim to improve the well-being of the state's children living with rare diseases.

Annette ensures that the rare disease community in Nevada has a significant presence and influence in state government. She plays a pivotal role in addressing the unique needs of people living with rare diseases and their families, providing all stakeholders with the opportunity to offer recommendations to state leaders on critical issues. Her focus centers on the imperative need for heightened awareness, improved diagnostic tools, and expanded access to affordable treatments and cures.

ANDRE HARRIS

Texas HB 181 and HB 1488

André is a third-year Ph.D. student studying Social Work at the University of Houston's Graduate College of Social Work. André serves on the Executive Board of the Sickle Cell Association of Houston and holds positions on several other advisory boards for sickle cell and rare disease stakeholders. He is a proud member of Phi Beta Sigma Fraternity, Inc. and serves as the National Sickle Cell Liaison Director, a position that allows him to strengthen the social action interests the fraternity has in supporting the sickle cell community.

Community Congress

Since 2015, the EveryLife Foundation's Community Congress has brought together patient organizations, industry leaders, and other rare disease stakeholders to provide advice and insight on urgent policy issues and Foundation programs and initiatives.

Thank You to Our 2023 Working Group Co-Chairs and members for their collaboration and hard work on the different projects that help advance policy for the rare disease community

For more information about community congress membership visit:
everylifefoundation.org/community-congress/

FEDERAL OR STATE ADVOCACY: YOUTH AND TEEN

SATI COOPER-MCCANN

Accelerating Kids' Access to Care Act

Raw gem faceting involves shaping and polishing to refract the light inside to maximize a stone's brilliance and fire. Her dispersion of light and luster began at 7 in self-awareness, self-efficacy, and community-building. This rare gem is a force for equitable and legislative good in rare healthcare 'on the Hill' and beyond. Her pillars of support include her mother, key family and friends, health specialists, medical mentors, virtual public-school teachers, pediatric ballet instructors, and community organizations. Advocacy has no age barrier as the youngest of many equitable actions: a Marfan Foundation Kids' Club peer, a public #LightUpForRare Event co-host, a Global Nation Rare Gem Campaign Addressee, an RDLA's 1st Ever Youth and Teen Hill Day and Rare Across America participant, and a Global Genes Rare Advocacy Summit panelist. She's sharing her excavation from local to global civil rights for rare disease patients as part of our rare collection, so we may radiate together.

SAMANTHA ROSE

RARE Act and Expanding Telehealth Access Act

Samantha Rose is a junior from Short Hills, New Jersey. She is a top student, former varsity tennis player, senior editor of the literary magazine, co-president of the Feminist Club, contributor to the science journal, and a peer leader, among other activities. She served a two-year term on the Board of Education Liaison Committee. She has been a year-round intern with RSDSA since 2021, inspired by her mother's struggles with Complex Regional Pain Syndrome (CRPS/RSD), and was appointed to its Advocacy Committee. She also has raised over $26,000 for RSDSA. She advocated before members of Congress at Teen Advocacy Day and Rare Across America, ardently pushing for more funding for rare disease research and other legislation. She is also a Young Adult Rare Representative (YARR). Samantha spent her summer doing biomedical research at the University of Pennsylvania. She also met with medical experts and researchers, hoping to find better treatments and a cure for CRPS. She is driven to combine her passion for science with her desire to make a difference and raise awareness for the rare disease community. She is as fierce an advocate as she is a tennis player and Yankees fan.

ZACHARY THOMAS

Newborn Screening in Alabama

Zachary Thomas is an aspiring advocate from the Gulf Coast of Alabama. His interest in policy and history began with a first grade President's Day project on George Washington and has continued since. His own diagnosis of MPS I fuels his passion for helping others through Newborn Screening. Zachary has advocated through state and federal programs for the past five years and vows not to stop until access is improved. In addition to his advocacy work, Zachary is an avid basketball and football fan and is a self-proclaimed flag aficionado.

JASMEEN ALDACO

Safe Step Act

Jasmeen Aldaco is a twenty-year-old HAEA Youth Regional Advocacy Leader originally from New Mexico. At the age of fourteen, she was diagnosed with Hereditary Angioedema with a Normal C-1 Esterase Inhibitor. Her experiences and interest in advocacy led her to pursue a degree from the University of Arizona majoring in Rehabilitation Studies and Services. Her diagnosis led to her dedication to advocacy and she has continuously advocated for causes that have a significant influence on people's lives. Her advocacy efforts extend to critical issues such as the Safe Step Act, supporting charitable assistance programs, and advocating for increased funding for rare diseases through the National Institutes of Health (NIH). Her dedication to advocacy reached an international level when she was selected as a LEAP program participant with HAE International (HAEi) and was given the opportunity to travel to Dubai and further enhance her advocacy skills on a global scale.

EMMALYN HUDSON

Medical Nutrition Equity Act; Access to Genetic Counselor Services Act; Accelerating Kids' Access to Care Act

Emmalyn Hudson is a 13-year-old born with a rare genetic metabolic disorder called Glutaric Aciduria/Acidemia Type 1 (GA-1). She was diagnosed at six days old through the newborn screening program in Mississippi. GA-1 is a hereditary disorder where the body lacks the necessary enzyme needed to break down amino acids, lysine, and tryptophan, which are building blocks of protein. There is no cure for her rare disorder, but she manages her health with specialized formulas and medications. In 2020 Emmalyn's mom founded a non-profit called Mississippi Metabolics Foundation and she helps spread awareness and advocate for newborn screening and rare diseases. In 2021 she won an EveryLife Foundation Rare Artist award for her painting "Escape from Reality".

JAKE JUIP

National Ataxia Awareness Day resolution, S. Res. 850

Jake Juip is 17 years old and a Senior at University Liggett School in Grosse Pointe, Michigan. He has a neurodegenerative disease called Friederich's Ataxia, which makes even the simplest of tasks - like walking, writing with a pen or pencil, using the restroom, and eating – more difficult each and every day. He hopes that his advocacy will result in a world that is just a little bit easier for people with disabilities and that my fundraising efforts will help support the scientific research to #SlowStopReverse and eventually #CureFA and other rare diseases.

Every year, Jake meets with senators and representatives during United Against Ataxia Hill Day, to advocate for support for his condition. Him and his family host an annual fundraiser which has raised more than half a million dollars over the seven years we've hosted it.

AYANA JOHNSON

Virginia H.R. 2084, 2085, 2086, and 2094, sickle cell bills

Ayana Johnson, an honors student and senior at Nansemond River High School, a classically trained violinist, a dancer at Governor's School for the Arts, a small business owner, and Miss Virginia's Teen 2022. She is an award-winning scholar with recognition from the National Honor Society, the National Beta Club, and the Suffolk Art League.

In particular, Ayana is an advocate for Sickle Cell Warriors. She serves as the Sickle Cell Disease Association of America's National Teen Ambassador. As an emissary, Ayana educates the public to negate the disparities and stigmas faced by those living with chronic illnesses.

Despite her busy lifestyle, Ayana has many interests, including playing classical violin, reading, listening to music, traveling, spending time with family, film & photography, and journaling.

JOYCE FITZ

Accelerating Kids' Access to Care Act

Joyce Fitz is a 15-year-old rare disease advocate. At the age of 2 years old, she was diagnosed with an ultra-rare 1 in 80000 disease, titled Schwachman diamond syndrome. This disease causes bone marrow failure and difficulties with the pancreas. Growing up, public speaking has been a passion of Joyce's and she uses that to empower others in the rare disease community, and demand change. Joyce has been working on 2 bills recently that she created, one for Medicaid and rare diseases, and the other being creating an awareness day for her disease. She strives to make a change to the United States healthcare system, specifically regarding the financial aspect and the aspect of quality.


Join the Young Adult Rare Representatives (YARR)!
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• Impact policy at the federal and state levels
• Develop your public speaking and leadership skills
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TRAVERE THERAPEUTICS

DIVERSITY EMPOWERMENT: PATIENT ADVOCATE OR ORGANIZATION

DIONNE STALLING

Rare and Black

Dionne L. Stalling is an extraordinary advocate and the driving force behind Rare And Black, an organization dedicated to raising awareness and support for Black individuals living with rare medical conditions. .She battles not one, but nine rare conditions, giving her a profound understanding of the challenges faced by those who live with such conditions.

Dionne works tirelessly to dismantle barriers to healthcare, promote research, and foster a sense of community among those often overlooked in the healthcare system. Her advocacy extends beyond awareness, as she strives to ensure equitable access to resources and support for this underserved population.

Her dedication and compassion have made her a beacon of hope and a powerful voice in the rare disease community. Her work at Rare And Black is a testament to her resilience and unwavering commitment to making a difference in the lives of others.

E.WE FOUNDATION

E.WE Foundation
A Healthcare Advocacy Organization

The E.WE Foundation is an IRS approved 501(c)(3) nonprofit healthcare advocacy organization. Kareem & Sarita Edwards founded the E.WE Foundation after becoming parents to Elijah, a vibrant little boy diagnosed in utero with Edwards Syndrome, Full Trisomy 18. The E.WE Foundation believes that early diagnoses and access to diagnostic therapies and resources can yield better health outcomes for chronically ill infants and children. For the Edwards, many of these therapies were delayed or denied due to the high mortality rate associated with Trisomy 18. The Edwards had to coordinate Elijah's healthcare by themselves. Today, Elijah's medical team consists of a local pediatrician and about 19 specialists at Children's of Alabama, an almost 2-hour commute one-way. The E.WE Foundation is committed to ensuring patient communities have equitable access to quality healthcare, mental health, health & financial literacy, and disease education. The E.WE Foundation is committed to raising awareness about Trisomy 18 and bridging the gap between diagnosis delivery and health care coordination.

MARY MCGOWAN

Foundation for Sarcoidosis Research

Mary McGowan has dedicated her career to speaking up for those who cannot speak up for themselves and for advancing the needs of underserved communities. During her 18 years at the American Academy of Pediatrics, she worked with our nation's leading pediatricians speaking up for policies that meet the needs of children. During her 8 years as the COO and CEO of WomenHeart, Mary built programs to address the needs of underserved women in clinical trials, saved lives through national screening programs and awareness efforts, and provided space for all underserved communities in public policy. In the last four years, Mary has brought this expertise to the rare disease community, leading the impactful African American Women and Myositis Campaign while CEO of TMA. As the CEO of the Foundation for Sarcoidosis Research (FSR), Mary has led a national Diversity Summit, established a national awareness campaign on African American Women and Sarcoidosis known as Ignore No More, reaching over 500,000 individuals, and is driving a national Accelerate Clinical Trial Equity in Sarcoidosis (ACTe NOW!) campaign to improve clinical trial engagement with Black Americans, and created and implemented a grassroots public health project to improve diagnosis and referral for underserved populations.

CARTER HEMION

Carter Hemion is a young adult rare disease advocate and writer. They learned they were born with classical Ehlers-Danlos syndrome at 20 years old. The diagnosis opened the door to identifying other rarely diagnosed comorbidities that progressed untreated for months or years because of delays in diagnosis. Carter is most passionate about self-advocacy at the intersections of rare disease with gender-affirming care and with neurodivergence and madness. They worked in Washington to recognize Ehlers-Danlos syndromes and Hypermobility Spectrum Disorder Awareness Month in 2022 and 2023 so fewer patients in the future will have to go as long without recognition, and they advocate in support of state organizations like the NW Rare Disease Coalition and Eastside EDS. They also advocate for cEDS and comorbidities at a federal level through writing articles, public speaking, meeting with legislators, and collaborating with other rare disease advocates.

ARTIST-TO-ADVOCATE

These finalists have utilized their artwork to advocate for federal or state legislation. Award exclusively sponsored by WCG Clinical

"From Pain to Purpose"
2022 Rare Artist Awardee

LAURA ROMANO

Laura Romano (They/Them) is a 26-year-old patient advocate from Groton, MA. They were diagnosed with Classical-Like Ehlers-Danlos Syndrome (clEDS) at the age of eighteen, and Hereditary Neuropathy with Liabiltiy to Pressure Palsies (HNPP) at the age of twenty-three. Laura is a graduate of the YARR Leadership Academy and a 2022 Rare Artist Awardee. Laura holds a B.S. in Neuroscience from Simmons University and is currently pursuing a M.Ed. in Early Childhood Education while working as a preschool teacher.

"Sprout"
2022 Rare Artist Awardee

WES BURIAN

Wes grew up in Canada exercising a creative obsession for building, drawing, and creating. He captured his childhood dream to create movies first working at Tippett Studio, as a Supervising Visual Effects Artist on many feature films. Next, he moved on to Dreamworks Animation as an Artistic Department Head where for 15 years he designed character and environment looks for many films including Shark Tale, Monsters vs Aliens, and Kung Fu Panda 1, 2, and 3. Wes has taught Master's level University Courses, International Computer Graphics Conventions, Community-Based Kids' Art Programs. He has since participated in Rare Disease Advocacy on and off Capitol Hill. Wes lives near Portland, Oregon, and is currently participating in a Gene Therapy Clinical Trial and always looking for more ways to further amplify all of our rare voices.

"The Black Hole"
2022 Rare Artist Awardee

AANYA KHATTAR

Aanya Khattar is a fifteen-year-old from California. For more than half of her life, it was just her and her mom. She's the one person she knows she can always rely on, so her heart dropped when she was diagnosed with an Arteriovenous Malformation also known as an AVM.

To spread the word about AVMs and aneurysms, Aanya became an ambassador for The Aneurysm and AVM Foundation. TAAF taught her how to effectively advocate to the best of her abilities. With the skills she'd learned over the years, she has tried her hardest to continue to make an impact in her community. It's been two years since Aanya's mom's surgery, and she can happily say that she came out strong. Aanya hopes that with awareness and further research, they can conquer this medical condition together.

"Elephant in the Room"
2022 Rare Artist Awardee

NELL CHOI

Nell Choi is a 15-year-old patient advocate, speaker, and author. Diagnosed with Neuromyelitis Optica at age nine, Nell developed a passion for storytelling that led her to publish her first book at age twelve, called My Hospital Story, to provide hope to others living with chronic illness. In 2022, Nell's elephant sculpture, titled "Elephant in the Room," became a RareArtist awardee. Since then, Nell has become involved in legislative advocacy, participating in both Rare Disease Week and Rare Across America, and she used her RareArtist piece to communicate her story to legislators. Nell is the first junior ambassador to The Sumaira Foundation for NMO. She has been a panelist at patient days and has moderated panel discussions with key opinion leaders at UCLA. Through her advocacy, Nell hopes to give voice to other young patients living with rare diseases.

CONGRATULATIONS TO ALL RARE DISEASE PATIENT ADVOCATES AND ORGANIZATIONS NOMINATED THIS YEAR

Kelly Considine
Elizabeth Kennerley
Jessica Graham
Patrice Sterling
Carolina Sommer
Sarah Bailey
UDN Patient and Family Advocates
Maria Pollock
Angelman Syndrome Foundation
Alexia Mays
Julie Rauch
David Law
Krystle Myers
Samantha Stallings
Princess Sherika Walls
Clio Lang
Rhiannon Perry

THANK YOU TO THE RAREVOICE NOMINATIONS COMMITTEE

David Eckstein, Office of Clinical Research, NIH
Wendy Erler, Alexion Pharmaceuticals
Stephen Groft, EveryLife Foundation Board Member
Carter Hemion, Young Adult Rare Representative
Sarah-Lloyd Stevenson, Amazon
Caitlin Van Sant, Mehlman Consulting

REGISTRATION FOR RARE DISEASE WEEK ON CAPITOL HILL 2024 WILL OPEN ON **JANUARY 3rd, 2024**

Save the Date: FEBRUARY 25TH – 28TH, 2024

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Yathish & Pawan, friends living with *Gaucher disease*, India

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